Genetic Testing: A Medical Revolution or The Next Inequality Crisis?

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I. Background

How much of your personal data can be read in your genes? And what is it acceptable to use this data for? The latter interesting question will be discussed throughout this paper, and hopefully lead to a better insight on the matter.

Directly analysing an individual's DNA is becoming more scientifically feasible nowadays, and could potentially play an important part of our future. Indeed, existence of such data would have an immediate positive effect, such as detection and prevention of fatal diseases, or diminution of crimes by enhanced DNA analysis. However, in other hands, such as health insurance companies or the common employer, it might rapidly lead to genetic discrimination. Even in the earlier case, if misused, it might have unrepairable repercussions, such as consent problems.

Genetic data is specific data about a person concerning their genes, which encode personal characteristics from eye color to likely future diseases. The action of withdrawing and analysing a person's genetic data is called genetic sequencing, or genetic testing, whenever the withdrawal is performed with a specific goal in mind.

The positive and negative effects of such data might be steered into the most desirable outcome by making sure a correct and reasonable policy in these regards is in place. Different rules, which both protect the people involved and ensure the correct usage of the data, must be introduced and enforced. We do not pretend to give the answer for a correct policy to be implemented, but aim to discuss possible impacts and recommendations on how to properly use genetic sequencing data.

These issues could be explained by answering the following main question;

How should genetic sequencing data be used in the health care sector?

Although a lot of interesting points of view may be adopted, we shall concentrate on the usage of genetic data in the health care sector and its surroundings. We shall thus not go into details about the possible economical and financial impact, nor the criminal and juristic point of view. Moreover, a wide range of DNA testing kits are offered by many private companies, however their scientific accuracy is disputable. We shall mainly focus on data obtained from scientific research.

Within the health care area, we aim to focus on multiple perspectives, which address the influence on a personal level, the impact on research and medicine, along with the possible discrimination based on medical data.

Firstly, we shall focus on an individual's mental health state after reception of results of a genetic test and their potential chance to adapt accordingly. This gives rise to our first sub-question; *Is it beneficial, on an individual level, to be aware of potential future illnesses?*

Next, we will look into how medicine could be shaped by this technology, and in specific how the information obtained by genetic testing could help

in medical research. Indeed, full knowledge about the general health conditions of a society would help steer research and funding, but acquiring such knowledge raises questions concerning consent and privacy. This leads to the next sub-question; *How could data from genetic testing influence medical research?*

Finally, we shall dive into the possible genetic discrimination that could occur in society, more specifically in insurance companies and with the common employer. Our last sub-question is thus; *How could genetic sequencing lead to discrimination?*

Before studying these subquestions, we will dive into how the genetic data is obtained and why it is important and relevant to study its impact on the health care sector nowadays.

There are multiple factors to take into account before selecting a method to obtain data, such as accuracy and financial aspects, as well as intended results. The Sanger method has been used for decades and still is. It has become more affordable over time, although it only analyses one DNA fragment at a time, leading to lower accuracy rates. Newer methods tend to be more informative, such as the Whole Genome Shotgun (WGS) which, although highly expensive and time-consuming, can focus on important sections which are hard for geneticists to analyse accurately, leading these methods to be, for some diseases, irreplaceable. There also exist cheaper methods like Next-Generation Sequencing, which reveals a lot of regions of the DNA at a time, unlike the Sanger method, but is more affordable than the WGS. Some methods are still being developed, such as the use of DNA-biochips, which would allow a closer accuracy rate of DNA reading to the WGS method with a low price. All these testing methods may seem informative enough today, but we should take into account that there are multiple unknowns in the DNA interpretations, such as, for instance, interactions between different genes [Suvorova et al., 2020].

Different obtention methods call for different uses. In the Unites States, roughly 15% of the population reports having used a home kit DNA test. These were bought from private companies, and were used mainly for family origin tracing [Graf, 2019], but gives an idea of an upper bound on the percentage of society in contact with genetic sequencing. According to Evertt Rogers [Rogers, 1983], we may classify the adopters of a technology in 5 different categories; innovators (The first 2.5% of population using it), early adopters (2.5% - 16% of the population), early majority (16% - 50%), late majority (40% - 84%) and laggards (84% - 100%). This mainly places the consumers of the new technology of genetic testing in the category of early adopters. In specific, the technology has not yet gone through its chasm, being the transition from a consumer range of early adopters to a consumer range of early majority. This transition is marked by a large investment and a switch to a larger production, often marking the failure of a technology [Zevenberg et al., 2022]. Indeed, if the process of genetic sequencing cannot become mass-produced at a reasonable price, it will never see the light of day as a viable solution for the average person.

Linked to the previous idea, we also see arising a Collingridge Dilemma, which states that the true impacts cannot be predicted until the technology is developed enough to make changes complicated [Collingridge, 1980], which is what we see in this scenario. At the moment, the technology is very little developed, and the future of it is still unknown, thus is very steerable. However, we are not yet certain about the possible side effects, and can only make educated guesses and predictions about them.

This is why studying the existing and possible impacts on society of genetic testing is important as soon as today. We are in a phase where it is still influentiable enough to reach a better version of it, and possibly already solve or avoid the negative effects. Keeping in mind the importance of the study, this paper will aim to, using different theoretical and practical approaches in combination with the three sub-questions stated earlier, answer the main and larger question stated in the start of this section.

II. Framework

Throughout this paper, we shall use several ethical and political frameworks in order to answer our questions.

Deontology [Zevenberg et al., 2022] is an ethical theory stating that actions are judged to be good or bad based on the intentions of the moral agents performing the action, and only the action in itself is judged. The reasoning behind a just action must be in line with one or more principles such as privacy, autonomy, justice, etc. The rules that must be obeyed in deontology are universal, meaning that they apply to everyone equally and that there are no exceptions. Immanuel Kant called this the categorical imperatives which can be summarised with the statement: "Act only according to that maxim whereby you can, at the same time, will that it should become a universal law" [Kant, 2017].

We shall use this ethical theory to analyse our first sub-question in contrast with the consequentialism point of view, which is another theory where only the final consequences of actions are taken into account to measure it´s moral value. In addition, only the foreseeable and intended consequences are considered [Zevenberg et al., 2022]. In the case of a dilemma, where both paths lead to some good and some bad consequences, the moral agent should perform the action that brings the greatest amount of happiness. To know which path leads to this one should perform the hedonic calculus which is the sum of the total happiness and total pain an action causes and for which we take into account their duration, intensity and certainty among other factors.

In many fields, there is a need for more than just ethical theories to guide the people working in it. One of those is medicine, where these theories have to be put into practice, is the area of medical ethics [Zevenberg et al., 2022]. Its foundation is the balance between non-maleficence and beneficence, which means that doctors must do what is best for their patients without harming them. Some of the principles of medical ethics are doctor-patient confidentiality, which protects the patient's right to privacy, and bodily autonomy, which allows for a patient to decide what happens to their body.

Since we are focusing on the use of genetic testing in the medical field, it is important to know what regulations medical professionals are expected to follow, especially since in some countries, they are legally bound to follow these rules [Rimmer, 2017].

Then, for the second question, we see an autonomy-welfare dilemma. On the one hand, there is the will to let the civilians operate on their own free will. On the other hand, there is the will to make everyone act in a way that is most beneficial for society as a whole. We approach this problem using the following two theories.

Firstly, the main body of bioethics is considered to be informed consent [Eyal, 2019]. According to Eyal, the main arguments for informed consent are about protection, autonomy, prevention of abusive conduct, trust, self-ownership, non-domination and personal integrity. They argue individuals have the right to follow their personal rules and decide about their own bodies so no patient is caused harm from their personal point of view. For instance, people with certain strong religious beliefs refuse to receive blood transfusions, although medically judged necessary [Sarteschi, 2004]. With informed consent, abuses and assault cases are less common as caretakers are not in arbitrary control of their patients, which helps maintaining the trust on health care professionals protecting the patients sense of personal integrity.

Secondly, we consider the harm principle. It is a concept within libertarianism [van der Vossen, 2019], a political philosophy that believes in individual freedom and the liberty to make you own choices. The idea behind it is the topic of John Stuart Mill's essay, 'On Liberty' stating; "That the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others."[Mill, 1869]

The last sub-question shall be viewed from a policy perspective. One of the key tools to tackle issues coming from science and new technologies are policies. They describe how different actors in a society should act in order to achieve a solution to a public problem [Zevenberg et al., 2022]. These controversies that need a policy can be classified as structured problems, that have high scientific and societal consensus; moderately structured, which either have low ethical or scientific consensus, and; unstructured, or wicked, problems that have both

low scientific and societal consensus. The less consensus there is, the harder it is to find a policy that satisfies the needs of all the actors involved in the controversy.

III. Is it beneficial, on an individual level, to be aware of potential future illnesses?

A lot of controversy is present on the topic of an individual's mental health after gaining knowledge about a test result for specific genetic diseases. It is a difficult topic to address, as there are multiple sides that influence the mental health of each human being, such as the severity, the controllability, and curability of the disease, and the perception of risk.

Additionally, it is challenging to measure these influences, as mental health is subject to an individual's feelings. Therefore, only qualitative research can be done where researchers can make use of scales, such as the State-Trait Anxiety Inventory, which measures the mental well-being of a person [Sydeman, 2018].

Having an advanced system for genetic testing might have benefits on the micro level. For instance, for different curable diseases, such as some cardiovascular diseases, the difference between the anxiety levels of a positive or a negative result is minimal after discussion with a professional about the cure and treatments available [Oliveri et al., 2018]. For the patient, it allows them to take the needed precautions.

The effects on mental health varies largely depending on the severity and curability of the disease. An illness that tends to have a large effect on the quality of life and does not have a known cure, such as Huntington's disease, which is a brain disease that progressively causes uncontrollable movements, leads to higher anxiety levels when an individual learns that they carry the mutation gene [Oliveri et al., 2018]. When no treatment is known for the disease, tests might lead to unnecessary stress for the tested person.

Additionally, since the technology used for genetic testing is still very new on the market, it has a certain degree of unreliability [Abraham, 2012]. Individuals might thus make life, career, or relationship decisions based on wrong results.

Next to the possible unreliability of the tests, a predisposition to a disease does not always imply the individual will develop the illness, other factors should be taken into account such as the environment or lifestyle [Abraham, 2012].

The effect on the mental health of a patient also relies on their perception of risk, since some people are naturally more stressed than others [Oliveri et al., 2018], as well as the emotional support they will have from their entourage, who in some cases are more affected than the actual patient [Marteau and Croyle, 1998]. It is therefore important to analyse the stress levels before and after testing when doing research on the effect of DNA testing on mental health, and differentiate not only between different diseases but also between different patients carrying them, and the support they receive from the outside.

Getting back to the question, being whether it is beneficial, on a purely individual level, to know about one's genetic test results, we will approach it from an ethical point of view. In specific, we shall recall that medical ethics relates to a balance between non-maleficence, and study the question from a deontological and a consequentialist point of view.

We start by considering the deontological perspective. In this case, the moral duty to not cause harm in any way, would be enforced by not revealing harmful information to the patient. Indeed, it is clear that a large scale testing would harm selected individuals, such as the ones attained by incurable diseases, or the ones seeing inaccurate results. From a deontological point of view, it is not morally accepted to disregard any group of people, no matter how small it is. A large scale testing would thus not be accepted in this perspective.

Secondly, we look at the question from a consequentialist point of view. Receiving a more or less definitive result would be beneficial for the larger part of society, as they would be able to make life choices depending on it and possibly improving their future. However, in some side cases, the results show false

positives or negatives, or reveal incurable diseases. Although for them the negative effect outbalances the positive effect on the micro level, the number of people positively affected outbalances the ones negatively affected, considering most people will not have a fatal incurable disease, and the overall utility would be increased by performing a large scale testing.

In both cases, it is possible to limit or reduce the negative effects by providing the required help before, during and after the process. It is possible to implement a policy, such as required for life-changing surgery [Dahlberg et al., 2019], to ensure a patient is mentally stable and has a caring entourage before undergoing such a test, and enforce that they get well-informed throughout the entire process.

To answer the question, the individual mental health can be affected in multiple ways depending on different factors. Of course, learning about a curable disease might be hard at first, but being able to treat or prevent it would eventually lead to a better life. However, learning about incurable diseases might cause an enormous, unnecessary amount of stress and anxiety. Additionally, the tests still have a degree of unreliability, such that the person might end up taking life-changing decisions which were not even needed in the first place. All these factors might affect the mental health state of the individual, but in either case less damage is caused whenever full information and sufficient support is provided.

IV. How could data from genetic testing influence medical research?

The term genetic screening is often used when performing genetic testing on an entire society. In this sub-question, we shall explain to which extent genetic screening, and medical testing on individuals, could influence the medical sphere.

If the general health condition of a society is available to the research area, pharmaceutical companies and medical research companies or universities would be able to steer their work in a more meaningful and consequent direction. Indeed, funding could be allocated more efficiently, and infrastructure could be built accordingly. In these regards, a general genetic screening would be beneficial for medicine and allow it to evolve faster in the areas most needed. As an example, we know air pollution has damaging effects, also on our DNA [Rider and Carlsten, 2019]. With a more extensive study of this damage, scientists could find new preventive treatments.

Moreover, the existence of such a database would, besides helping to steer research, also allow researchers to study the given disease with more empirical data. Knowing what a healthy person, who might be diagnosed with the disease at a later stage in life, looks like on a molecular level, gives more information about the disease, and would influence the path towards a cure. As such, it would help avoid the onset of a disease to a certain extent, or maybe even prevent it in general.

A large problem nowadays consists of mistreatment of certain diseases. Some treatments are severe and lead to unavoidable side effects. Although medicine has improved a lot, it still happens that patients are misdiagnosed and thus not only not get treated properly, but additionally get a wrong treatment [Saini, 2021]. A complete genetic test could increase the accuracy of diagnoses large factors, and avoid patients getting cured for the wrong illness.

Another current problem with treatments is that multiple genetically different diseases get classified under the same category. For instance, lung cancer is fundamentally a mutation in the individual's DNA. Although the variation is similar for all cases, it might occur in different parts of the DNA, leading to different treatments being more beneficial. This could lead to personalized treatments, where the disease is being handled differently for each individual depending on their genetic data [Roche Foundation Medicine, 2022]. Being able to read and analyse the DNA would thus lead to more precise and efficient treatments.

It is thus clear that medicine would improve largely by the existence of more advanced genetic testing technologies, by creating improved, new, more specialized or more personalized treatments. However, these improvements in the medical sphere can only occur if most of the society is willing to participate in a large scale testing, leaving no room for having

outsiders not wanting to get tested. This gives rise to an autonomy-welfare dilemma, in which the autonomy of an individual is regarded as their choice to decide to take the test, whereas the welfare is regarded as the benefit to society if everyone does so. This thus gives rise to the ethical dilemma of when it is morally accepted to breach an individual's consent for a greater benefit in society.

It is not unseen in the medical sphere to not require full informed consent [Johns Hopkins Berman Institute of Bioethics, 2014]. Indeed, expert bioethicists have agreed that it sometimes requires too much time and might cause more harm to the patient, acting like an obstacle. This occurs for instance in the case of life-changing operations. In this case, only a superficial, uninformed consent is given, which very much resembles no agreement at all. The same might be applied in this case, as the positive consequences could outweigh the negligence of consent. One could thus argue that the consent of the patient could be disregarded.

However, the core of bioethics is informed consent. Unlike the previous case, in which there was no time for it, genetic data is not urgent to analyse. To the extent to which it is possible, we should obey the fundamental rules of medical ethics, which involve informed consent. Not requiring permission clearly breaches autonomy of the individual, by not leaving them a choice, and self-ownership of the data obtained from testing, since it is not totally clear what the data will be used for, which are some main principles of informed consent.

The individuals getting the genetic tests are usually not medical professionals, and thus do not have the necessary knowledge to understand the full implications of the test. They thus cannot give a well-informed consent, as their expertise lie outside the domain. However, given the principle of bodily autonomy, ethically speaking it is still their body which is getting tested, so it remains in their power to accept or not. There is thus a thin line between getting a superficial consent and neglecting it, but is that a line we want to cross?

This could be related to a recent issue regarding Covid-19 vaccines. Indeed, for the greater good of society, it was important to get as many individuals as possible vaccinated. However, should the individuals be given a choice? King laid out arguments as to why such vaccines could be made totally mandatory [King et al., 2022], which may also be applied to genetic testing. From a libertarian point of view, this would be accepted, since consent may be neglected if justified as preventing harm to others, according to the harm principle. In this case, getting full consent from everyone might be a long and tedious procedure, and there will always be outliers not willing to participate. As such, adopting the harm principle would make it feasible to impose a genetic test.

Other than individual consent, it is also important to consider the family surrounding the person. Genes do not only have their information, but also some part of their relatives, making it possible to have very precise knowledge of someone's DNA without having them tested. For a larger scale, although an individual patient gives their consent towards genetic testing, since the results also will reflect and have an impact on their family, they should be involved in the decision as well [Abraham, 2012].

Thus, for genetic screening to give us relevant results that could help shape the health care system to evolve more efficiently, the population from which DNA samples are taken need to be an accurate reflection of our society. Indeed, the more people participate, the more accurate results will be. This gives rise to the importance of consent and when it would be reasonable to disregard it. Although this could have an incredible impact in health care, the autonomy of an individual should come first, and they have to understand what consequences might come from this.

V. How could genetic sequencing lead to discrimination?

With the rise of genetic testing, there is some concern of a new type of inequality, namely genetic discrimination. One of the major concerns in the medical sector is the use of the results by insurance companies. They could benefit themselves by having access to a DNA database, but restricting them such access could also have disadvantageous consequence on the insurance mar-

ket [Suvorova et al., 2020]. However, discrimination could also occur during interview processes at companies, which would look into the interviewee's DNA before making their decision [Wallace, 2004].

On one hand, with insurance companies having access to someone's genetic information, they can decide to adapt the price of the insurance covering a certain medical treatment per individual. This would mean that people with "unhealthy" genes will end up having to pay a more expensive insurance than people with "healthy" genes. Since one cannot choose or adapt one's genetic data, some people would be disadvantaged when it comes to the price of health insurance from birth, which leads to a new type of socio-economic divide and genetic discrimination [Wallace, 2004]. This issue between civilians and insurance companies has already been raised in multiple contexts, such as a citizens jury in which they presented both side of the arguments to a group of civilians in order to learn their opinion of the matter [Bennett and Smith, 2007]. Additionally, laws have been introduced in different countries. In France, genetic data may only be used for scientific and medical purposes, and not obeying this might lead to prison time and a relatively large fine [Bélisle-Pipon et al., 2019]. However, in other countries, such as Switzerland, results of genetic tests may be used if the insurance policy is over a certain financial threshold, and seeks to remove this limit.

On the other hand, if the insurance companies do not have access to genetic information, but the individuals do, people may take advantage of this blind spot, often referred to as adverse selection [Godard et al., 2003]. Indeed, if individuals know they do not have a genetic predisposition to a certain disease, they will not want their insurance to cover the corresponding treatment. On the same line of reasoning, patients who do have this predisposition will want the treatment to be included. This would mean that the premium previously computed by insurers are no longer going to be enough to pay for everyone's treatment and the cost of insurances will have to increase, or insurance companies would go bankrupt. It is worth noting that the previously article is limited since it is only an expected result.

Furthermore, besides inequality in the insurance sector, the common employer could benefit from genetic data and discriminate against its employees or interviewees [Wallace, 2004]. Indeed, an employer usually prefers a healthy employee, who will have few sick days and stay at the company for a long time. Part of such information is readable in the worker's genes, and requiring such a genetic test could thus lead to another form of genetic discrimination. The second title of the Genetic Information Non-discrimination Act of 2008, an act passed by the United States Congress to protect employees and companies from genetic discrimination, states that DNA information may not be involved in hiring, firing, promoting, training, or any other aspects of employment [Spiggle, 2020]. American employers thus cannot make use of such information, although existent, which is a good solve if enforced correctly.

However, the usage of genetic testing in companies might not always lead to purely negative effects [Department of Labor et al., 1998]. It is sometimes used to detect whether a prospective or already employed employee is susceptible to a certain disease the workplace environment might cause them to develop. It may also be used to study the effects of the workplace environment, by analysing the genetic changes an employee occurs after a certain amount of time.

Due to the novelty of the genetic sequencing technology and the field of genetic medicine, it is difficult to predict how it will affect society. Moreover, it is hard to know what the consequences of its use in the insurance sector will be. One can make a model on what the effects could be but since there are no countries where health insurance companies have total access to the genetic information of their clients, there could be some unforeseen consequences of this scenario, especially as the limits of genetic medicine have not been reached yet. Thus it is important to take a step back and try to think of the possible outcomes, and already start implementing policies preventing the negative usage of the technology.

Also, the idea of allowing health insurance companies to ask for the genetic information of people who are seeking for an insurer might also lead to

some debate in society, making it a wicked problem. We know that these are the problems for which it is the most difficult to find a solution that everyone agrees with. As stated earlier, even the use of genetic data in order to determine insurance policies are close to illegal, however preventing them from using any of this data would lead to adverse selection. There is thus a need for a middle ground, in which nor civilians nor the insurance companies would be discriminated. Part of the solution could be to allow insurers to access the general results of genetic screening of the country or region where they operate, or an anonymous database that gives the genetic information of each individual but not linked to the person's identity. In such a situation, insurance companies could still adapt to the newly born technology, and improve their services accordingly by being prepared for the future, without easily getting played by individuals.

As for the usage of genetic testing on an employer side, it is clear it should generally be avoided to prevent any kind of discrimination. However, if monitored correctly, it might lead to some positive outcomes. It should thus not directly be banned from a company use, but it is important to force certain regulations.

We conclude that the results of genetic tests can cause genetic discrimination by insurance companies or employers and some countries have already taken legal steps to avoid this. However, these are mainly access restricting regulations, which could also be harmful. There is thus a need for a policy that integrates both sides of the argument in order to protect all the actors involved.

VI. Conclusion

Because of the lack of certainty about what can arise from genetic sequencing, it is important to already try to predict its impacts and steer it on a safe and positive trajectory. The technology is still in its early stages, and a lot of improvements are still required before it can be a viable large scale medical testing method, so it is still possible to direct it in an ethically correct direction.

On an individual level, test results might help individuals adapt their lifestyle and possibly prevent the disease, but they might also damage the individual's life on a mental level. The usage of genetic testing might be justified and frowned upon from a consequentialist and a deontological perspective respectively. It is important to consider each case separately and provide the necessary help such as psychological guidance to patients getting results that might impact them on a mental level.

From a medical point of view, genetic testing could clearly lead to great advances in science. However, these advances would be the more remarkable if everyone participates in the testing process, giving birth to an autonomy-welfare dilemma, leading us to ask ourselves whether it is acceptable to breach the consent of an individual. Although arguments for both sides exist, it remains clear that consent is a corner stone of our modern society and one cannot ethically justify neglecting it.

Genetic testing could also lead to genetic discrimination, where an individual is judged depending on their genes. In such cases, insurance companies could adapt their prices for each individual, or employers could pick their employees on the basis of good genes. However, the prevention of access to the data could lead to adverse selection, and the usage of genetic screening in the common companies might help certain susceptible applicants from not developping fatal diseases. There is thus a need for a policy balancing the usage of the data, without handicapping neither the companies, nor the civilians.

It is important to note the novelty of this topic also limits the knowledge that we have on its effects in medicine and even other aspects of society that we have not discussed in this paper. We should also consider that as it progresses more, decisions made now might rapidly become out-dated.

Our aim in this paper was to discuss the impacts of and give recommendations on the use of genetic data by analysing the problem through the question; How should genetic sequencing data be used in the health care sector? Overall, it is clear that genetic testing might have both positive and negative consequences on all levels. On a positive note, it would improve medicine in general and decrease morbidity rate, but on a negative note it might harm some

individual's mental health, restrict the liberty of society and give rise to a new type of discrimination. It thus raises the question; To which extent are we willing to give up liberty for the advance of science?

VII. References

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